Table 1: Literature assessing patient experience of health care transition preparation across various health conditions

Multiple Complex Conditions		
Study Design	**Description**	**Reference**
Cross-sectional Survey-based; young adult report	This study examined factors associated with receipt of health care transition (HCT) counseling services as reported by young adults. The 2007 Survey of Adult Transition and Health (SATH) was used to explore self-reported receipt of transition support. Of 1865 SATH respondents, 55% reported that their health care providers had discussed how their needs would change with age, 53% reported that providers had discussed how to obtain health insurance as an adult, and 62% reported having participated in a transition plan. Only 24% reported receiving all three transition counseling services. Provider-youth communication was associated with increased health care transition guidance.	Sawicki GS, Whitworth R, Gunn L, Butterfield R, Lukens-Bull K, Wood D. Receipt of health care transition counseling in the national survey of adult transition and health. *Pediatrics.* 2011;128(3):e521-529.[12]
Cross-sectional Survey-based; parent report	This study analyzed data from 17,114 parent respondents to the 2009–2010 National Survey of Children with Special Health Care Needs, which was fielded to assess transition preparation among youth with special health care needs (YSHCN). With only 40% of YSHCN receiving elements of recommended transition care , researchers concluded that most YSHCN are not receiving needed transition preparation. Although most providers are encouraging YSHCN to assume responsibility for their own health, far fewer are discussing transfer to an adult provider and insurance continuity.	McManus M, Pollack LR, Cooley WC, et al. Current Status of Transition Preparation Among Youth with Special Needs in the United States. *Pediatrics.* 2013;131(6):1090-1097.[11]
Cross-sectional Qualitative; young adult, caregiver, and provider report	To examine transition experiences, including facilitating practices and obstacles, this study analyzed focus groups and interviews of 143 young adults with disabilities and special health care needs, their family members, and their health care providers.	Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics.* 2005;115(1):112-120.[45]

	Findings showed that pediatric and adult-oriented providers represent different medical subcultures. Young adults' and family members' lack of preparation for successful participation in the adult health care system contributes to problems with health care transition was common.	
Cross-sectional Survey-based; parent report	This study aimed to provide a baseline measure of the proportion of US children who meet the six Maternal and Child Health Bureau's (MCHB) core outcomes for youth with special health care needs (YSHCN). One of these core outcomes is that youth will receive the services necessary to make transitions to adult life, including adult health care, work, and independence. Results from the 2001 National Survey of CSHCN (n=38,866) and the 2001 National Health Interview Survey (n=13,579) showed that only 6% of youth aged 13 and older are receiving the services needed to successfully transition. These services include support and communication about changing to an adult provider and changing health care needs with age.	McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics.* 2004;113(5 Suppl):1538-1544.[46]
Autism		
Cross-sectional Survey-based; parent report	This study examined the receipt of HCT services in youth with autism spectrum disorder (ASD). The 2005–2006 National Survey of Children with Special Health Care Needs (NSCSHCN) was used to examine receipt of HCT services for youth with ASD. Only 14% of youth with ASD had a discussion with their pediatrician about transitioning to an adult provider, less than a quarter had a discussion about health insurance retention, and just under half had a discussion of adult health care needs or were encouraged to take on appropriate responsibility.	Cheak-Zamora NC, Yang X, Farmer JE, Clark M. Disparities in transition in planning for youth with autism spectrum disorder. *Pediatrics*. 2013. 131(3):447-454.[47]

Cancer Survivorship		
Cross-sectional Qualitative interview and focus group based; youth, young adult and parent report	This study sought to determine barriers or facilitators to transition from pediatric to adult-centered survivorship care as perceived by Latino adolescent and young adults (AYA) cancer survivors and their parents. Twenty-seven Latino AYA (aged ≥15 years) completed interviews, and 21 Latino parents participated in focus groups. Both AYA survivors and parents identified two major facilitative factors for survivorship care: involvement of the nuclear family in care at the adult setting and inclusion of symptom communication in late effects discussions. Barriers included perceived stigma of a cancer history and emotional trauma related to discussions about the childhood cancer experience.	Casillas J, Kahn KL, Doose M, et al. Transitioning childhood cancer survivors to adult-centered health care: insights from parents, adolescent, and young adult survivors. *Psychooncology*. 2010; 19(9):982-990.[48]
Cross-sectional Survey-based; adult report	This study assessed knowledge of adult survivors of childhood cancer about their primary cancer diagnosis and therapies. A telephone survey of 635 survivors was conducted. Overall, 72% accurately reported their diagnosis with precision and 19% were accurate but not precise, compared with medical record documentation. History of receiving a written medical summary, attending a long-term follow-up clinic, and anxiety about late effects were not associated with greater knowledge. Investigators noted that these knowledge deficits could impair survivors' ability to seek and receive appropriate follow-up care.	Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA.* 2002; 287(14):1832-1839.[49]

Congenital Heart Disease		
Cross-sectional Qualitative interview based; youth and parent report	This qualitative study explored how 50 youth and 28 parents affected by congenital heart disease (CHD) and cystic fibrosis (CF) negotiate constructions of 'normal developmental time' in both anticipating and dealing with the transition from adolescence to adulthood. Concerns related to deteriorating health and occupational restrictions in the future were paramount for youth with CHD and CF. For young women, the loss of 'normal' gendered roles was also a concern. Attending to youth's temporal anxieties and future concerns may enhance the transition process for youth with CHD and CF.	Moola FJ, Norman ME. 'Down the rabbit hole': enhancing the transition process for youth with cystic fibrosis and congenital heart disease by re-imagining the future and time. *Child Care Health Dev.* 2011; 37(6): 841-851.[50]
Cross-sectional Survey-based; young adult report	This study aimed to determine the percent of young adults with congenital heart defects (CHDs) who successfully transferred from pediatric to adult care and examine correlates of successful transfer. Two hundred thirty-four patients aged 19-21 completed the measure. In the total cohort, 47% had transferred to adult care. More than one quarter of the patients reported having had no cardiac appointments since 18 years. Successful transfer was associated with more pediatric cardiovascular surgeries, older age at last visit to the pediatric hospital, recommended follow-up at a CACH center, patient beliefs that adult CHD care should be at a CACH center, and attending cardiac appointments without parents or siblings.	Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004; 113(3 Pt 1):e197-205.[51]

Cystic Fibrosis		
Cross-sectional Survey-based; adult report	This study surveyed adult CF patients on their concerns regarding a transition program. A survey was sent to members of the International Association of Cystic Fibrosis Adults (IACFA), n = 334. The majority of patients (81%) received care from a CF center. Nearly one-fourth of patients seen at a CF center continued to receive care from a pediatrician (mean age 30 years). Those patients seen in an adult program described criteria for their transfer to the adult program, but no findings suggested a standard transition program. The patients reported their level of concern about transfer as minimal, far less than what CF physicians had perceived, which may impede successful transition of patients into an adult program.	Anderson DL, Flume PA, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatr. Pulmonol*. May 2002;33(5):327-331.[52]
Cross-sectional Qualitative interview and survey-based; youth and young adult report	The purpose of this study was to investigate how adolescents and adults with CF view preventative counseling and their transition to adult-centered care within a children's hospital. Thirty-two patients ≥16 years old diagnosed with CF were recruited from a pediatric tertiary care setting to undergo interviews and complete a self-administered questionnaire on preventive counseling by health care providers and transition issues. Participants felt that 13-16 years of age was the best time for them to begin spending time alone with their main doctor. Less than half of the participants recalled receiving preventive counseling during the previous 12 months. Qualitative data emphasized the importance of independence in making decisions in health care and establishing relationships with providers, and many patients did not desire to transfer care to an adult hospital. Participants identified adult-focused services such as inpatient rooms, discussion groups, work options, and social service support that would enhance care.	Zack J, Jacobs CP, Keenan PM, Harney K, Woods ER, Colin AA, Emans SJ. Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatr. Pulmonol*. 2003; 36(5): 376-383.[53]

Cross-sectional Interview and survey-based; youth and parent report	To aid in the development of CF specific transition guidelines, a pre-transition questionnaire and post-transition interview were used to assess the concerns and expectations of 60 CF patients and their parents as they underwent transition from pediatric to adult care. The two most important concerns identified by patients prior to transition were potential exposure to infection and having to leave their previous caregivers. Introduction to the adult CF team prior to transition was associated with lower levels of concern in all areas. Parents' most significant concern was the ability of their child to care for their disease independently.	Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr. Pulmonol*. 2001; 32(6): 428-436.[54]
Cross-sectional Survey-based; young adult and adult report	This study examined participation in health behaviors, health locus of control, and negotiation of developmental tasks of adulthood with 75 patients with CF, aged 18–42 years old. Participants completed the Multidimensional Health Locus of Control Scale. Results indicate a number of behaviors for which respondents had not yet assumed responsibility, such as managing medical insurance and nutrition. Respondents were compliant with their medical regimen currently than when first assuming responsibility for their health as adolescents.	Hamlett KW, Murphy M, Hayes R, Doershuk C. Health independence and developmenal tasks of adulthood in cystic fibrosis. *Rehabilitation Psychology*. 1996; 41(2): 149-160.[55]
Cross-sectional Survey-based; parent report	This study described the development and psychometric properties of a survey tool designed to evaluate children's level of independence in their CF treatment, as this may have a direct effect on their involvement in treatment and adherence. The Self-Care Independence Scale (SCIS) was completed by parents of 76 CF patients (ages 4-17 years). Results support the SCIS as a sound measure of CF self-care independence. The SCIS may be used as a screening tool for adolescents preparing to transition to adult CF centers care.	Patton SR, Graham JL, Varlotta L, Holsclaw D Jr. Measuring self-care independence in children with cystic fibrosis: the Self-Care Independence Scale (SCIS). *Pediatr. Pulmonol*. 2003; 36(2): 123-130.[56]

Cross-sectional Survey-based; youth and young adult report	A survey of adolescents and young adults with CF attending an adult CF center was conducted to evaluate a transition program as a means of transferring care from pediatric to adult setting. Forty patients completed a self-administered questionnaire. Most thought that the transition program made the change from pediatric to adult care easier. Of the 40 patients, 17 (42%) recommended that other patients go through the transition program. Twenty-six patients (65%) preferred the adult program. These findings suggest that adolescents with CF should be encouraged to transfer to an adult CF center once they have reached an agreed-upon age.	Nasr SZ, Campbell C, Howatt W. Transition program from pediatric to adult care for cystic fibrosis patients. *J. Adolesc. Health.*1992;13(8): 682-685.[57]
Type 1 Diabetes		
Cross-sectional Survey-based; young adult report	This study examined characteristics of the transition from pediatric to adult care in emerging adults with type 1 diabetes and evaluated associations between transition characteristics and glycemic control. A survey was developed and mailed to 484 diabetic adults aged 22-30 years, receiving adult diabetes care at a single center. Current A1C data were obtained from the medical record. Response rate was 53% (n = 258). The mean transition age was 19.5 ± 2.9 years, and 34% reported a gap >6 months in establishing adult care. Common reasons for transition included feeling too old (44%), pediatric provider suggestion (41%), and college (33%). Less than half received an adult provider recommendation and <15% reported having a transition preparation visit or receiving written transition materials. Respondents who felt mostly or completely prepared for transition had lower likelihood of a gap between pediatric and adult care. There was no independent association of preparation with post-transition A1C.	Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: young adult experiences and relationship to glycemic control. *Diabetes Care*. 2012; 35(8):1716-1722[5]

Cross-sectional Survey-based; young adult report	Youth with type 1 diabetes are at risk for poor glycemic control as they age into adulthood. The aim of this study was to describe sociodemographic and clinical correlates of poor glycemic control associated with the transfer of care from pediatric to adult diabetes providers. One hundred eighty-five adolescents ≥18 with recently diagnosed type 1 diabetes participated. At a follow-up visit, 57% had transitioned to adult diabetes providers. The estimated median age of transition of care was 20.1 years. Older age, lower baseline glycosylated hemoglobin, and less parental education were associated with increased odds of transition. The odds of poor glycemic control at follow-up were 2.5 times higher for participants who transitioned to adult care compared with those who remained in pediatric care.	Lotstein D, Seid M, Klingensmith G, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. *Pediatrics.* 2013;131(4):1062-1070.[58]
Cross-sectional Survey and qualitative interview-based; adolescent, young adult and parents report	Participants completed questionnaires and responded to open-ended questions regarding self-management, self-efficacy, expectations and experiences with pediatric and adult care providers across the transition process. At a mean age of 16.1 years, most pre-transition adolescents had not yet discussed transferring care with their parents or doctors. Although many post-transition young adults reported positive interactions, several described challenges locating or establishing a relationship with an adult diabetes care provider. Qualitative themes emerged related to the anticipated timing of transfer, early preparation for transition, the desire for developmentally appropriate interactions with providers, the maintenance of family and social support, and strategies for coordinating care between pediatric and adult providers.	Hilliard ME, Perlus JG, Clark LM, et al. Perspectives From Before and After the Pediatric to Adult Care Transition: A Mixed-Methods Study in Type 1 Diabetes. *Diabetes Care.* 2014; 37(2):346-354.[59]

Human Immunodeficiency Virus (HIV)		
Cross-sectional Qualitative interview based; youth, young adult, and parent report	Semi-structured interviews were conducted with 40 perinatally infected adolescents (mean age 17 years), currently receiving care in a pediatric infectious disease clinic and 17 guardians, about their expectations related transition. Many adolescents reported that they did not know what to expect out of the transition. Others looked forward to increased responsibility and control, while some expressed concerns over leaving their current providers. Most guardians viewed the transition to adult care as a tool to facilitate maturity. Several indicated they had not discussed transition with their child and were waiting for their child to initiate the discussion. The results indicate a need for improved communication between youth and providers to enhance transition success.	Fair CD, Sullivan K, Dizney R, Stackpole A. "It's like losing a part of my family": transition expectations of adolescents living with perinatally acquired HIV and their guardians. *AIDS Patient Care STDS.* 2012; 26(7):423-429.[60]
Inflammatory Bowel Disease		
Cross-sectional Survey-based; youth report	This study sought to determine whether adolescents with inflammatory bowel disease (IBD) have developed key skills of self-management prior to the age at which many transfer to adult care. Adolescents aged 16 to 18 years old in the Boston Children's Hospital IBD database (43 total) responded to a mailed survey assessing knowledge and confidence of their own health information and behaviors. Respondents could name medication and dose with confidence but had very poor knowledge of important side effects. Most patients deferred responsibility mostly or completely to parents for scheduling appointments, requesting refills, or contacting provider between visits.	Fishman LN, Barendse RM, Hait E, Burdick C, Arnold J. Self-management of older adolescents with inflammatory bowel disease: a pilot study of behavior and knowledge as prelude to transition. *Clin. Pediatr. (Phila).* 2010; 49(12):1129-1133.[61]
Cross-sectional Survey-based; youth report	This study evaluated the knowledge of 78 adolescents ages 14-18 with inflammatory bowel disease (IBD) and 64 of their parents. Patients and their parents completed the MyHealth Passport for IBD and	Benchimol EI, Walters TD, Kaufman M, et al. Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool. *Inflamm. Bowel Dis.* 2011;17(5):1131-

	responses were evaluated for accuracy using medical records. Patients and parents were equally likely to answer questions correctly regarding disease characteristics and treatment, but not health services resources. Most patients accurately identified IBD classification and listed medications. Neither patients nor parents accurately identified disease location or previous investigation results. Parents were more likely to name insurance provider and pharmacy location. Future educational interventions should target areas of weakness in adolescent knowledge.	1137.[62]
Kidney Disease and Transplant		
Cross-sectional Survey-based; youth, young adult, and parent report	The goal of this study was to develop a measure of transition readiness for adolescent kidney transplant recipients. The Readiness for Transition Questionnaire (RTQ-teen; RTQ-parent) was created to assess overall transition readiness, adolescent health care behavior, and familial involvement in health care. Participants were 48 adolescent kidney transplant recipients, ages 15-21 years and 32 of their caregivers. Adolescents completed the RTQ-teen and self-reported measures of adherence. Parents completed the RTQ-parent. The RTQ showed good internal consistency, inter rater reliability, and demonstrated construct validity. Increased adolescent responsibility and decreased parental involvement predicted higher transition readiness. Greater adolescent adherence factors predicted greater transition readiness.	Gilleland J, Amaral S, Mee L, Blount R. Getting ready to leave: transition readiness in adolescent kidney transplant recipients. *J Pediatr Psychol*. 2012; 37(1):85-96.[44]
Cross-sectional Survey-based; youth and young adult report	The purpose of this study was to describe and compare mastery of health care management in adolescent (aged 14-17 years) and young adult (age ≥ 18 years) recipients of a liver transplant expected to transfer from pediatric to adult care settings. Fifty-two liver transplant recipients completed the Developmentally Based Skills Checklist, which asks how often	Annunziato RA, Parkar S, Dugan CA, et al. Brief report: Deficits in health care management skills among adolescent and young adult liver transplant recipients transitioning to adult care settings. *J. Pediatr. Psychol.* 2011; 36(2):155-159.[63]

	patients independently engage in specific health care management skills. Overall, young adult patients reported greater health care management than adolescents. However, less than half of the young adults surveyed reported consistently managing their liver disease independently, making their own appointments, and understanding insurance issues.	
Cross-sectional Survey-based; youth, young adult and parent report	This study aimed to determine adolescent and young adult liver transplant recipient (LTR) and parent perceptions about the transition process. Participants included 46 LTR (mean age 16.6 years) and 31 parents. Recipients and parents reported moderate concern about transition. LTR ≥16 yr reported greater health care responsibility and increased thought, interest, and knowledge about transition. LTR perceive having more independence than their parents are report.	Fredericks EM, Dore-Stites D, Lopez MJ, et al. Transition of pediatric liver transplant recipients to adult care: patient and parent perspectives. *Pediatr. Transplant.* 2011;15(4): 414-424.[64]
Rheumatologic Disease		
Cross-sectional Survey-based; parent report	This study used data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to determine the proportion of adolescents with arthritis who receive health care transition (HCT) services and compared the rates with those reported for adolescents with other special health care needs. Parents of youth with arthritis (n = 1,052), diabetes (n = 389), and other special health care needs (n = 18,189) responded. Many adolescents with arthritis are being encouraged to assume self-care responsibilities (74.8%); fewer discussed changing health needs in adulthood (52.1%), acquiring insurance (22.5%), or transferring care to a provider who sees adults (19.0%). These results are similar to youth with other special health care needs, but behind youth with diabetes.	Scal P, Horvath K, Garwick A. Preparing for adulthood: health care transition counseling for youth with arthritis. *Arthritis and Rheumatism*. 2009;61(1):52-57.[65]

Cross-sectional Qualitative focus groups and interviews; youth report	This study sought to explore the self-management needs of adolescents with juvenile idiopathic arthritis and the acceptability of a Web-based self-management program. A convenience sample of 36 adolescents who varied in age, gender, disease onset subtype, and disease severity were recruited from 4 Canadian tertiary care pediatric centers. Individual (n=25) and 3 focus-group (n=11) interviews were conducted Adolescents articulated how they developed effective self-management strategies through the process of "letting go" from others who had managed their illness (health care professionals, parents) and "gaining control" over managing their illness on their own. The 2 strategies that assisted in this process were gaining knowledge and skills to manage the disease and experiencing understanding through social support.	Stinson JN, Toomey PC, Stevens BJ, Kagan S, Duffy CM, Huber A, Malleson P, McGrath PJ, Yeung RS, Feldman BM. Asking the experts: exploring the self-management needs of adolescents with arthritis. *Arthritis Rheum.* 2008; 59(1):65-72.[66]
Sickle Cell Disease		
Cross-sectional Survey-based; young adult report	The goal of this study is to assess transition readiness of patients with sickle cell disease (SCD) in a transition program and to evaluate a SCD-specific assessment tool that measures 5 knowledge skill sets and 3 psychological assessments. Of the 47 patients between the ages of 18 and 22, 33 completed the assessment. The majority of patients reported good medical knowledge of SCD. There were knowledge gaps in the areas of independent living skills. A majority of patients reported being worried that SCD would prevent them from doing things in their life; however, few said they were worried or anxious about transitioning to adult care.	Sobota A, Akinlonu A, Champigny M, et al. Self-reported Transition Readiness Among Young Adults With Sickle Cell Disease. *J. Pediatr. Hematol. Oncol.* 2014. doi:10.1097/ MPH.0000000000000110. [67]
Cross-sectional Survey-based; youth and young adult report	This study sought to assess adolescent SCD patients' preparation for transition and identify variables that predict patient readiness. Seventy adolescent patients (14 to 20 years) receiving care at a pediatric SCD center completed a survey about the transition from pediatric to adult care.	McPherson M, Thaniel L, Minniti CP. Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatric blood & cancer.* 2009;52(7):838-841.[68]

	Mean readiness scores were low, with greatest deficiencies in prior thought, knowledge, anticipated difficulty, and interest regarding transition. Younger age was associated with less knowledge and interest; disease severity was associated with lower interest but greater anticipated difficulty. Adolescents with SCD demonstrate poor preparation for transition to adult-oriented care.	
Cross-sectional Interview-based; youth and young adult report	This study identified concerns and expectations of pediatric SCD patients as they begin to transition to adult care, as well as what program priorities they perceive would facilitate a smooth transition. Data were collected by means of interviews. The sample included 172 adolescents with SCD aged 14 years and older still in pediatric care within community-based and medical center SCD programs. The top concerns of adolescents were: lack of information relating to their transition; fear of leaving their familiar health care provider, fear that adult providers might not understand their needs; belief that an SCD transition program was needed; information provision about adult care programs; ways to meet adult providers; and ways to help health care providers understand their needs.	Telfair J, Ehiri JE, Loosier PS, Baskin ML. Transition to adult care for adolescents with sickle cell disease: results of a national survey. *International journal of adolescent medicine and health.* 2004;16(1):47-64.[69]
Cross-sectional Survey-based; youth, young adult and parent report	This study determined the issues, concerns, and expectations of adolescents and young adults with SCD and primary caretakers with regard to transfer to adult care. Results revealed that adolescents and young adults with sickle cell disease were concerned about how they would pay for medical care and how they would be treated by adult providers. Caretakers were concerned about their teens leaving pediatric care and assuming responsibility for care. All three groups reported mixed emotions about leaving pediatric care.	Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult, and parent perspectives. *J. Adolesc. Health.* 1994; 15(7):558-565.[70]